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ABSTRACT

This discussion looks briefly at the developmental tasks of adolescence to see how and if they apply to disabled youth. Topics discussed include disability as a stigma and how that affects the development of self-concept. The discussion is then interrelated to Schildkrout, Shenker and Sonnenlick's (1980) study, entitled "Human Figure Drawing in Adolescence," by exploring drawings made by hospitalized adolescents. The concluding section of the article compares the 1980 American study with a study interviewing disabled Australian adolescents and focusing on their views of the effects their disability has had on them as persons. Drawings and brief analyses of patients are included. (RH)

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Selected Papers

Number 42

Foundation for Child and Youth Studies

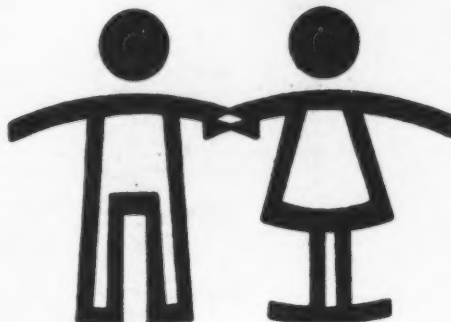
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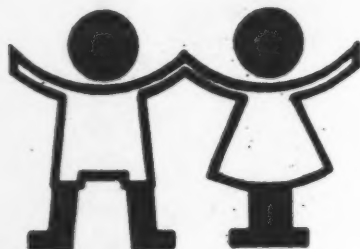
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YOUTH AND DISABILITY: ITS EFFECT ON THE PERSON

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YOUTH AND DISABILITY

ITS EFFECT ON THE PERSON

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In a copy of the New York Times, September 3rd, 1982, Evan Kemp who has had a neuromuscular disease for 34 years writes complaining about the Jerry Lewis Muscular Dystrophy Association Telethon. He states, "With its emphasis on "poster children" and "Jerry's kids" the Telethon focusses primarily on children - by celebrating disabled children and ignoring disabled adults, it seems to proclaim that the only acceptable status for disabled people is their early childhood. The handicapped child is appealing and huggable - the adolescent or mature adult is a cripple to be avoided. Even the Association's emphasis has unfortunate implications. The Telethon's critical stress on the need to find cures supports the damaging and common prejudice that handicapped people are "sick". As sick people, it follows that we should allow others to take care of all our needs until a cure is found".

Perhaps it is partly due to this avoidance of the handicapped adult and adolescent that only limited research work has been done in this area; whereas with children a vast array of information is readily available. What I intend to do is to look briefly at the tasks of adolescence, to see how and if they apply to the disabled youth, and to discuss disability as stigma and how stigma affects the development of the self-concept. Then I shall tie this in with work on "Human Figure Drawing in Adolescence", exploring some drawings of hospitalised adolescents and finally, I shall compare this New York study with that of some disabled adolescents I interviewed, ascertaining from them the effects their disability has on them as a person.

Adolescence is both a physiological and psychological formative period. The normal tasks of adolescence are stress-producing for all youngsters. The teenager who is undergoing the development of an adult body needs to adapt to his/her new self image. The rapidity of the growth and development which are occurring is only exceeded by the changes which occurred in the first year of life. A relatively homeostatic organism is suddenly disrupted by an outpouring of hormonal substances which effect dramatic changes in the adolescent. The altered endocrine state causes a marked increase in height and weight and the burgeoning of secondary sex characteristics with new body sensations.

Accompanying these physiological events is a heightened awareness of peers and a need for acceptance by both the same and opposite sex, often conflicting with a desire to draw back to the comfort and security of childhood.

In the later years of adolescence the need to make a career choice places additional demands upon the maturing youth. This choice of work possibility is compounded today with limited opportunities and, therefore, greater competition in respect of the positions available. Even the gaining of a tertiary qualification is no guarantee of a position in the workforce. To state it simply, the tasks of adolescence are summarised by the answers to a series of questions.

"Who am I?"	an identity question
"Where did I come from?"	an origins question
"Where am I going to?"	a directional question
"Who is going with me?"	a relational question
"What shall I do or be?"	a vocational question

These kinds of questions are just as much the concern of the disabled youth as the non-disabled. Perhaps they ask another question, "Why should this happen to me?" - a meaning to suffering question. It is in this charged state of emotional development that the presence or onset of a physical illness, in upsetting normalcy, tends to promote dependence at a time when independence is so vital. The real or imagined threat to body image during adolescence can be more traumatic and difficult to cope with than at any other time in life. Susan Nussbaum, a paraplegic who has become an activist for the rights of disabled people, reflected on her thoughts after a freak car accident left her spinal cord irreparably damaged. "Suddenly I was one of those people my mother used to tell me not to stare at on the street. I thought if I didn't die in the hospital, I would kill myself when I got out." (Jones, 1984).

Chronic illness in adolescence is especially tragic. It is emotionally unacceptable to patient, family and hospital staff. There is no more challenging patient to deal with than a hospitalised adolescent. Their needs are devouring, their hostility open, their demands insatiable and their protective denial of their serious illness tenuous.

A recently published book called "Social Stigma, the Psychology of Marked Relationships" (Jones), examines the interactions between a so-called normal person and the bearer of a "mark" that defines him or her as deviant, flawed, limited, spoiled or generally undesirable. In our terms the "mark" is one of disability which a person has that makes him/her different. The disabled child or adolescent views him/herself according to the label they are given. This stigmatising has a marked effect upon the development of the self concept. Hazel Markus (1984) writes "The development of self-concept is a distinctly social process. A discrediting mark or stigma necessarily modifies this social process and the interpersonal relationships that are so vital for self-knowledge and self validation. For the stigmatised individual, the reactions, observations, and evaluations elicited from other people may be disproportionately negative". An individual then actively constructs a self-concept from the information contained in his or her unfolding experiences, particularly those that involve the self-relevant responses of other people. With respect to stigmatising attributes or qualities of the self, it follows that individuals may attend to a mark, build a self schema around it and thus ensure its position as an important element of the self-concept. In order to give meaning to their existence one would expect that the disabled person would need to build their view of themselves to include their disability - studies indicate they find difficulty doing this and, in fact, frequently deny it. Self-esteem is usually considered to be a summary evaluation of the attributes of self or the extent to which individuals are satisfied or pleased with themselves. Stigmatised people tend to have low esteem - they do not measure up to society's view of being male or female because of their handicap.

Steve Sandler (1984) did not like to talk when he was young. Other children would laugh at him and mimic him when he stuttered. Bullies would beat him up after school. Sandler said he remembers when family and friends

reacted negatively to his early stuttering habits, "I became very anxious about it" he said. Stuttering persisted when he was in primary school, "The other kids laughed at me and I became more and more afraid to talk ... " In high school he would be afraid to ask girls out for dates and didn't socialise much ... "I was afraid of rejection" he said. Once in college, Sandler asked a girl out on a date, "She said no because I stuttered and that devastated me". The odd person out is the one who experiences stigmatisation ... there is security in being with fellow sufferers. A deaf person becomes a member of a deaf community and their self esteem is increased. As part of the deaf community individuals are able to view themselves as less marginal and to direct their attention away from their deafness to other qualities.

There are a handful of empirical studies on the self-concept of the stigmatised. In one study (Richardson, et al in Schildkrout et al, 1980) children aged 9-11 were asked to describe themselves. Their impairment included cerebral palsy, post polio impairments, cardiac disorders and diabetes. While both boys and girls talked openly about their handicap, the boys seemed more affected by it than the girls, presumably because they were more self-schematic with regard to physical activity. Whereas the girls turned easily to non-physical activities, the boys had greater difficulty finding compensatory activities. As a consequence they expressed more difficulties in interpersonal relations and attempted to use humour in their attempts to gain acceptance. The research seems to indicate that individuals who are fat or crippled or deaf may think in terms of "what they are not" or "what they cannot do". This type of self-knowledge explicitly invokes contrast with other people. However, they can also have a very clear understanding of their own strengths and abilities. The table on the next page found in Jones (1984) illustrates the difficulties of the person with a disability and the effects of that persons' disability on a friend.

The work by Schildkrout, Shenker and Sonnenblick on "Human Figure Drawing in Adolescence" was a means of broadening their understanding of young people. Adolescent patients (aged 12-19) as an initial task on their first visit to the clinic were asked to draw a whole human figure and one of the opposite sex. They collected 1500 drawings from this source and as the clinic was part of a general hospital, they also asked adolescent in-patients to do the drawings.

The technique was not new; it had been done many times before, mainly with children but not with adolescents.

They are quick to point out that the drawings alone cannot make a diagnosis. A drawing is a piece of behaviour, which is symbolic of the individual's total self at the time. Because no two individuals are alike in past history, social and intellectual maturity and personality adjustment, two similar drawings may have different symbolic meanings.

Brody (Schildkrout et al, 1980) states, "The first inside picture which the human individual has of himself is an image of his body". If this image is intact in early childhood, later stresses may not necessarily destroy it. For the great majority disturbances of body image are a central problem at some time during the span of adolescent years. Because of the instability of their ego ideals and their overdependence on the real and fantasised judgements of peers, adolescents are highly vulnerable to anxiety over their body image. Adolescents are notably intolerant and ashamed of even the mildest physical defect in themselves. Physical illness, even of a minor degree, causes an exceptionally severe personal blow to the adolescent's self-esteem. It provokes regression at a time of life particularly suscep-

*The Effects of Traumatic Stigma
on the Informal/Voluntary Relationship*

Feeling and Concerns Affecting the Relationship

<i>Stigmatized Person (Traumatic stigma, e.g. paraplegia)</i>	<i>Long-Term Friend</i>
Overattribution to stigma	Need to redefine relationship (if (based on activity like a sport)
Withdrawal	Denial of stigma in hopes of rein- stating old relationship
Denial of stigma	Revulsion
Desire to tell friend about special needs, unable to ask for or accept help	Withdrawal out of courtesy to imagined sensitivity to stigmatized person
Bitter, inconsolable	Feels happy the trauma didn't happen to self
Uncomfortable about special needs, unable to ask for or accept help	Feels vulnerable to death and disease
May feel infantilized, patronized if help is given by the friend	Desire to help, not knowing what to do
Fears other is remaining friendly out of pity	Ambivalence
May fear causing revulsion and fear in friend	Project feeling of own despair onto stigmatized person vis-a-vis stigma. I would feel terrible and overwhelmed if this happened to me
New role relationship (if friendship based on activity together, like sport)	Rationalize way out of relationship
May interpret other's passivity as rejection	Desire to keep reminders of past from stigmatized person
Envious of friend being normal	Fear of the condition itself (contagion)
Ambiguity about care needed or desired	Overattribution to stigma
Wonders what friend's other friends and acquaintances will think of the stigma	Blame stigmatized person for burden stigma places on relationship
Wonders if friend would be ashamed that he has the condition	Guilt over negative feelings
	Ambiguity about how to help
	Will I always have to help if I offer to help now?
	Will I be this person's only friend if I continue in the relationship?

tible to backwards movement. Most commonly, the adolescent deals with the anxiety provoked by illness with the unconscious mechanism of denial. In the drawings this is reflected by the removal of the affected part of the body. Sometimes the affected region is distorted or the illness exaggerated. The line drawings revealed an enormous range in the maturity level in a 7 year age span 12 - 19 years. "What we see more commonly than we anticipated are adolescents even as old as 19 drawing the human figure at levels expected of normal children under the age of 12". The researchers involved were a Child Psychiatrist, a Paediatrician, and a Psychologist and the drawings were studied without prior knowledge about the patient, the clinical notes being added later.

D.K.

Age 13

Male

I.Q. 89

The patient has multiple physical handicaps, including dwarfism and subtotal blindness. He is diagnosed as having Morquio's Disease, spondyloepiphyseal dysplasia congenita, and is only 3 feet tall.

Drawings: They are compensatory in size. There is significant absence of the eye in the male and an absence of the pupils in the female. The figures are Frankenstein-like monsters, either a projected wish to have such power or the way he perceives himself or others in the world around him. The female's big teeth make her particularly threatening. The absence of detail is correlated with his immaturity, low average intelligence and lack of visual acuity. He seems to feel empty. The broken lines, especially in the outline of the male, reveal intense anxiety.





Patient was born with arthrogryposis, a condition characterized by multiple joint deformities. He has had many operations and was admitted for further corrective surgery, which he refused. Psychiatric consultation revealed that he feared anesthesia and was disappointed with the results of last year's operation. He is extremely anxious about his future in every respect.



Drawing: The figure is amputated at mid-thigh level, revealing how "castrated" and helpless he feels. The large head emphasizes his strongest attribute—intellect. The nose is typically phallic. The eyes are staring and angry, while the mouth is a rigid line. The midline emphasis and the hand moving into the body show somatic preoccupation, while the outstretched hand with mobile, normal fingers reveals his wish to move out into the world. The buttons denote dependency.

The patient was admitted to the hospital for the surgical correction of prognathism (protruding lower jaw). He also suffers from a spastic colon. His parents and siblings are riddled with illness: diabetes, hypertension, coronary disease and mental illness.

Drawings: There is a marked difference in the techniques of the two drawings, and in their levels of maturation. The patient drew a female first, possibly his mother. The right side of her face and body are omitted, as well as the lower half of her body and left hand. This type of global omission demonstrates a state of extreme anxiety over body integrity, which one would expect in a family threatened by multiple major diseases. The shading of the left cheek is probably related to specific anxiety concerning the patient's impending mandibular surgery.

The male drawing is readily acceptable as a self-portrait. The distorted face has a huge jaw concealing the neck. Is he wearing a surgical gown and cap? The right hand appears to be waving good-bye. The drawing is of much poorer quality than the first, a reflection of how the patient feels about himself. The shading and slashing lines are further evidence of anxiety about body mutilation.





D.M.

Age 19

Male

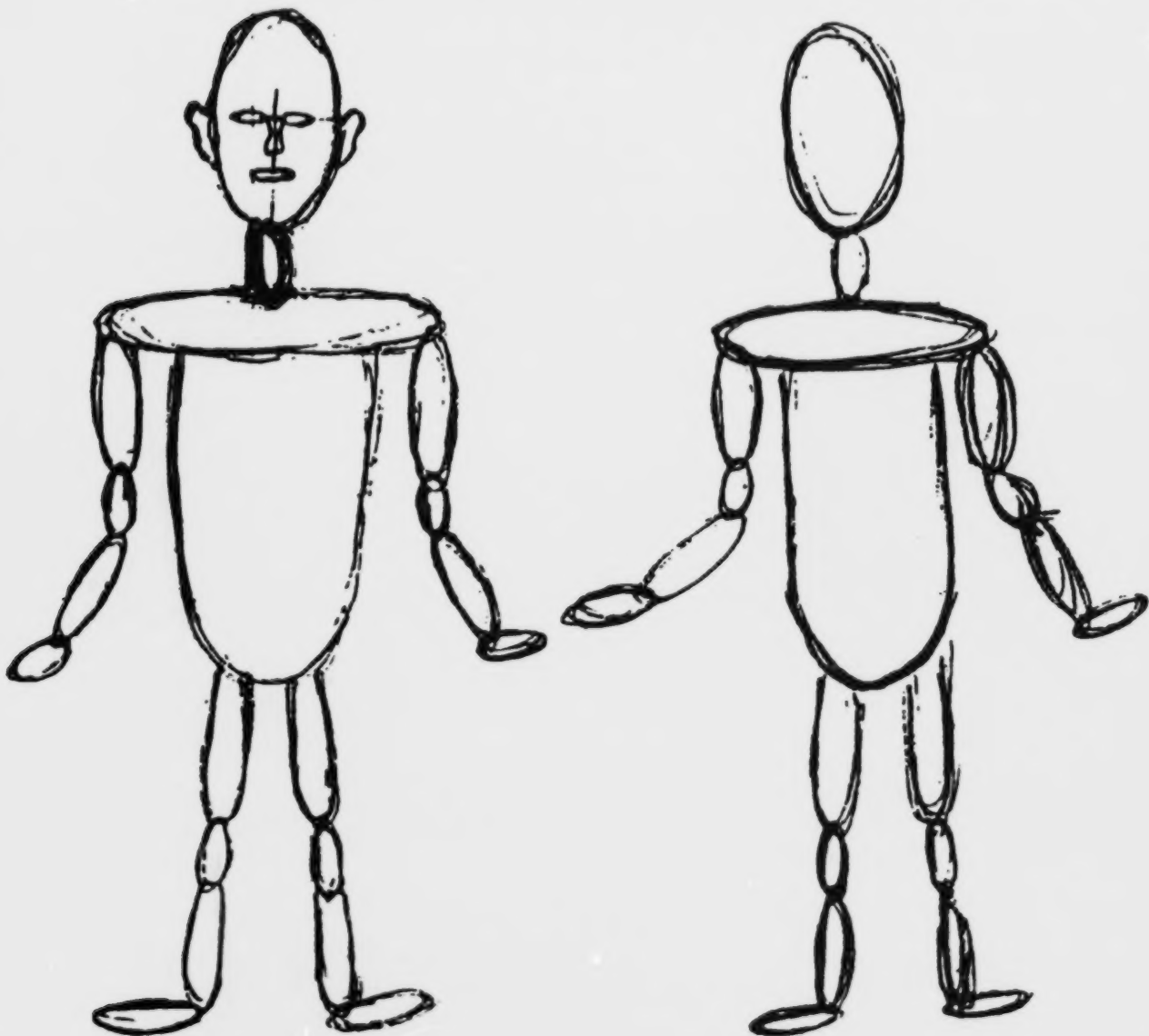
The patient was admitted to the hospital because of a large testicular swelling. He was operated on and found to have a testicular tumor.

Drawings: These were obtained one week after surgery. It is obvious that he is concerned with the genital area, protecting it with hands in both the male and female drawings. The crossed legs of the male heighten the inaccessibility of his swollen, vulnerable testes. The girl's thumb suggests a phallus. The heavy shading of the clothing and the ground line, although appropriate, are signs of anxiety. The male figure has a worried facial expression.



The patient was admitted to the hospital with swollen glands, pallor and fatigue. Diagnosis of acute lymphoblastic leukemia was made and the patient started on anti-leukemic medication. He had been ill for several weeks prior to admission.

Drawings: The patient draws typical armature figures indicating feelings of being non-human, manipulated by others. This type of drawing may be transient in nature, reflecting the concerns of the moment. The undifferentiated "female" figure is faceless. Drawings show depression, emptiness, suspicion, all of which are reality based in light of the patient's physical condition. The rigid armature may reflect an adaptive attempt to deal with overwhelming anxiety, by not allowing it to reach full consciousness.



The drawings assisted in uncovering unsuspected conflict and anxieties, thus helping the health care team to more adequately deal with the patient. "A most striking feature of this group of drawings is the projected feeling of being helpless and manipulated". This comment referred particularly to the hospitalised patients, some of whom were disabled.

The researchers comment in their conclusion, "Adolescents are especially disturbed by any illness that affects their physical appearance, suffering intense shame, sometimes without basis in reality. Obesity, one of the most common afflictions of this age period, does not appear in a single one of the drawings of patients with this condition. Instead, an idealised, wished-for body is often presented. In cases of life-threatening illness one is struck by a number of drawings of dehumanised armatures (p 11).

The ideas expressed by Schildrout et al, provided me with a context in which to visit a Special School and talk with a group of disabled teenagers. All of these young people have debilitating diseases, requiring regular medical assistance, and all of them have spent long and frequent periods in hospital. Some of them had their diseases diagnosed fairly early in life - for instance the persons with Spina Bifida, and those with Muscular Dystrophy, while for others an accident had rendered them disabled - e.g., one young lad being involved in a motor vehicle accident in an overseas country.

I was interested in discovering whether the drawings local young people provided would include the same fantasy of body-image and/or the dehumanised pictures, as well as the "lifelessness" element.

My introduction to this class of 10 teenagers - made up of 8 males and 2 females was by the teacher who indicated I would explain the reason for being in their classroom and what I would like from them.

On the initial visit I told them something about myself and then asked each of them to tell me something about themselves. What interested me about the method of introduction was the fact that in turn each one gave their name, then their disease - e.g. "I'm Joe, I'm a Spina Bifida".

It would appear that their view of themselves was determined by their disease - this was uppermost in their minds! On the next occasion I visited the school I said to the teacher, I was interested in the way the students introduced themselves. She said she was taken aback as it was the first time to her knowledge they had all stated their disease as the reason for being in the school.

Yet, as I thought about it in terms of "stigma" and of the statement "that the individual actively constructs a self-concept from the information contained in his/her unfolding experiences particularly those that involve the self-relevant responses of other people", I understood in part why they stated these things about themselves.

The reality of it is they are disabled and are labelled, and they tend to view themselves in terms of that label. I guess it is an all-consuming part of their existence. Life as they know it is governed by that label. The limited freedom they experience as individuals is always set within the bounds of that label.

After stating name and disease they spoke about the things in which they were interested - the girls indicated passive interests like TV shows, making things etc., all realistic and within the limits imposed by their disability. The boys on the other hand spoke of sports, motor cars, etc, all of which, in practical terms, they were unable to participate in themselves. Males traditionally are interested in action-oriented sports so they made their responses accordingly.

I explained to them the title of this paper and said I felt it important to get from disabled young people themselves, what they felt the effect of their disability had on them. I merely asked them to think about it and on my next visit 2 days later, we would talk about it.

This discussion was divided into two parts:

1. Drawing of male and female figures
2. Discussion on disability.

1. *Drawings*

The instruction for this was simply to draw a whole male and female figure. I have selected a few of these drawings and will briefly comment on them.

(A) Female aged 14 (Cerebral Tumour)

The picture of the female reveals a distorted body-image - it suggests that with no arms, "I'm useless". In the exaggerated nose for both the female and male figures some would see a phallic symbol. The face has a smiling mouth. The male picture suggests boys are more capable - has arms flung out wide. The genital area is clearly identified with a penis which is somehow boxed-in. A similar box appears in the female form. Do these suggest they are hidden - private parts or by being "hemmed-in", is it that they are present but of limited use for sexual expression?

(B) Maled aged 12 (Arthritis - youngest student)

The male picture appears stiff and rigid - a lack of flexibility and limited movement. Does this reveal something of how he sees himself or feels about himself - I would suspect it does. Both figures are dressed. The male has a very heavy beard in perhaps an over-emphasis on masculinity. The face is so fully covered that it is hard to see any facial expression (perhaps it's better to hide the pain!). The female picture appears freer and the face has a brighter happier appearance.

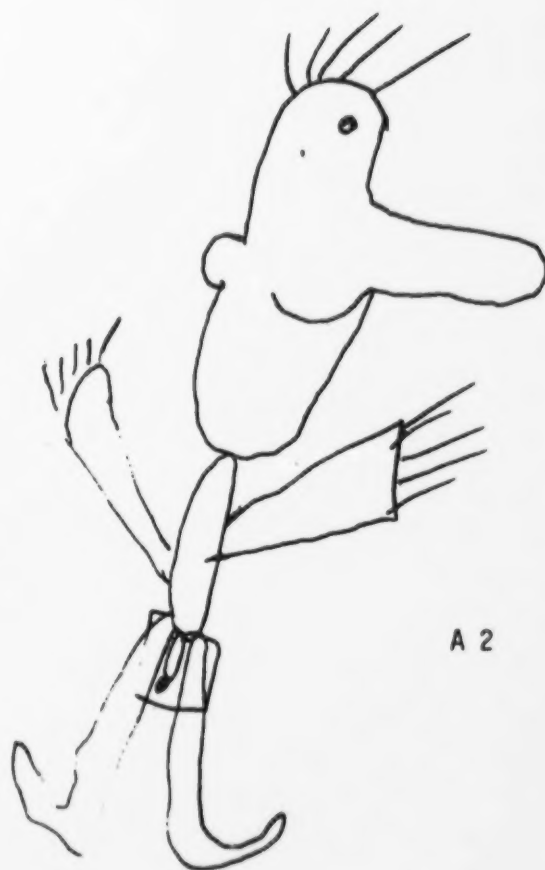
(C) Male aged 15 (Spina Bifida)

This young man was the biggest in the class and was generally big for his age. For identifying his drawings he wrote - 15 Male (not sure). An interesting comment when his picture is cut off at the waist - does it suggest impotence or uncertainty about male sexual identity? He is an alert young man - the male face appears fairly mature. The girl - full-figure drawing appears more vital and alive, complete with tennis racquet. The variations between the 2 figures are interesting.

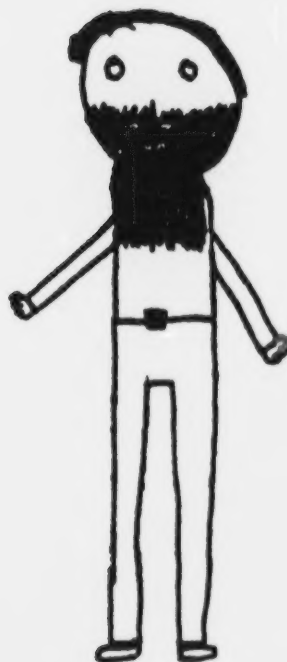
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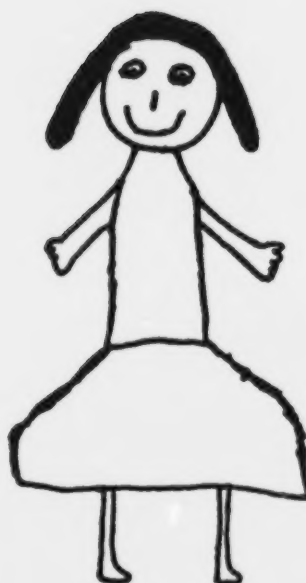
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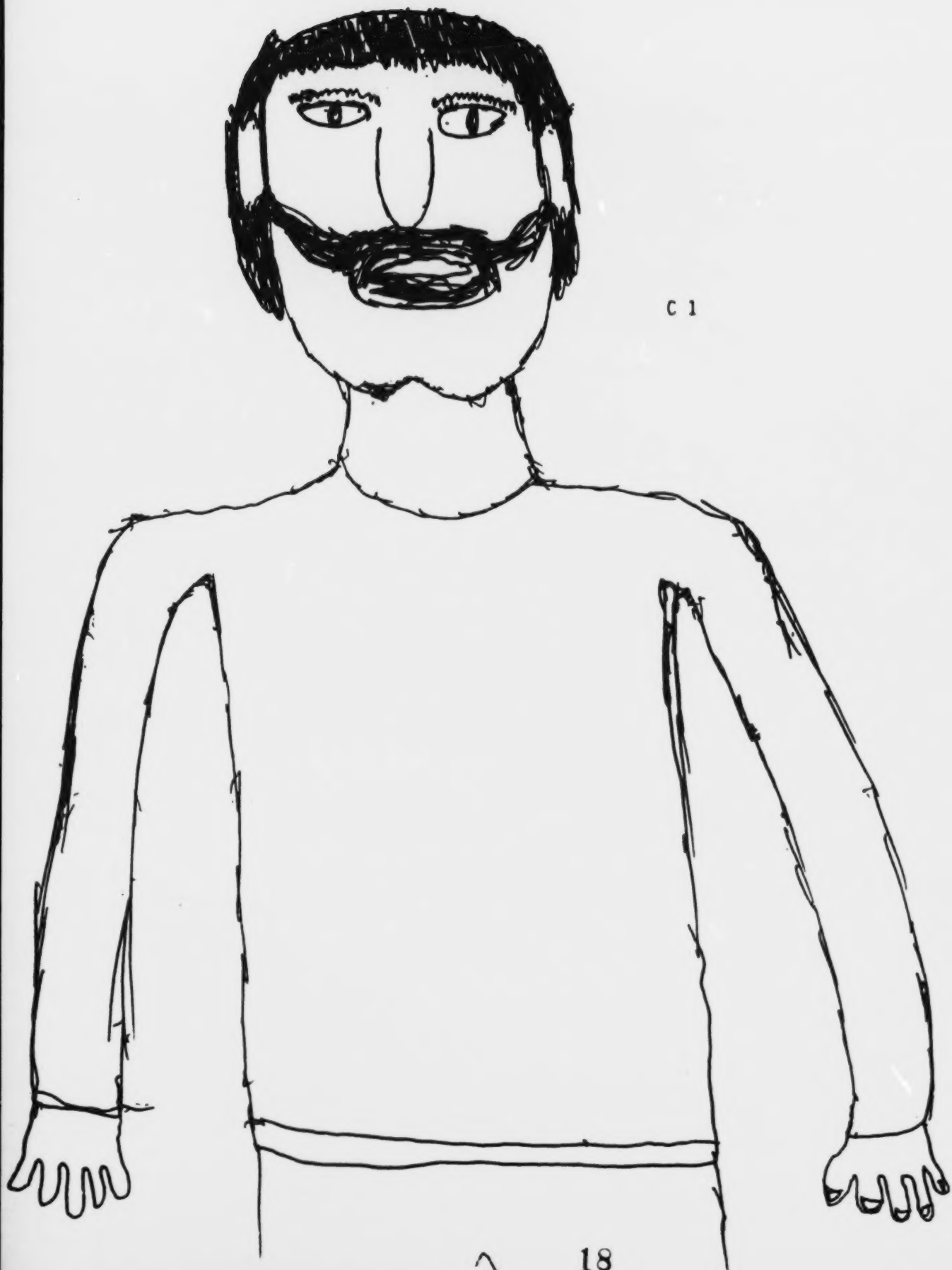


B 1



B 2





C 1

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C 2



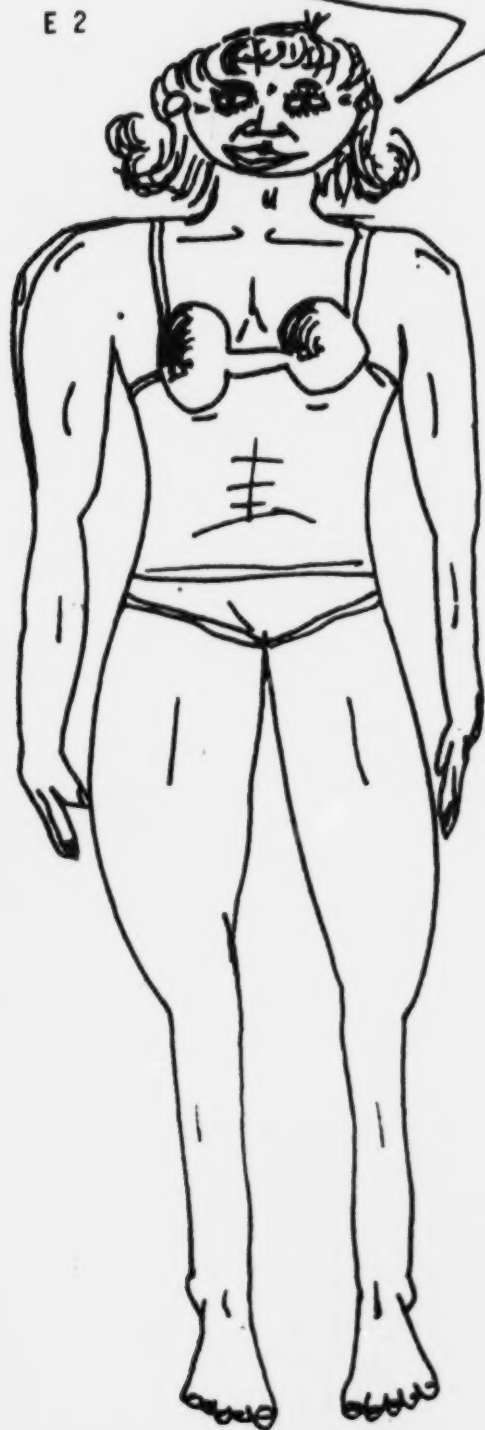
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D

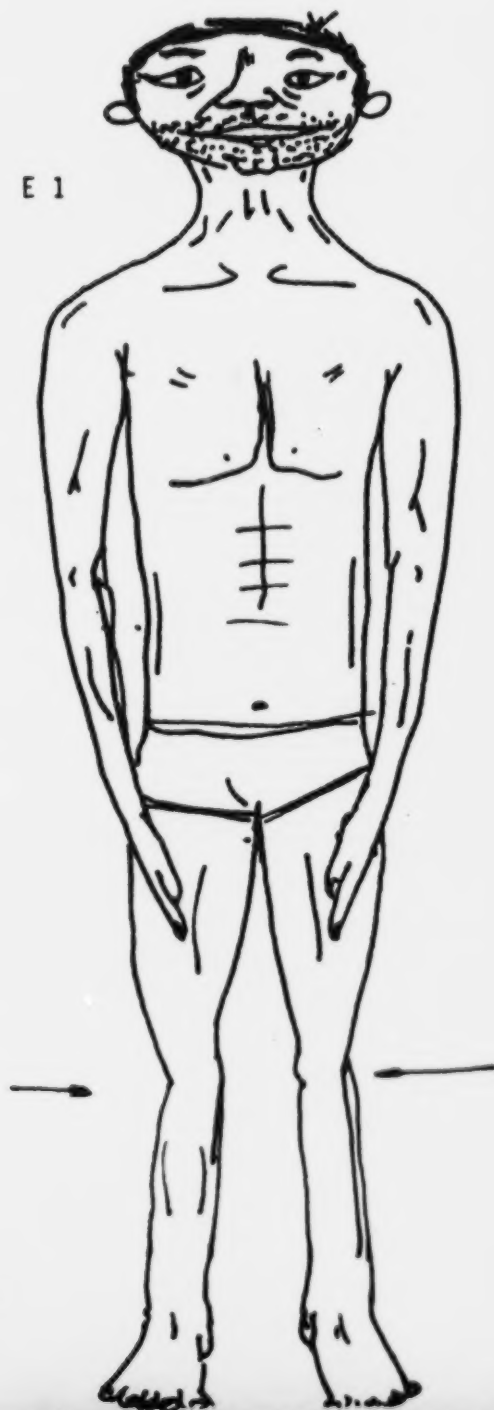


"What am I ever going to
do about my build?"

E 2



E 1



(D) Male aged 17 (Muscular Dystrophy)

These 2 figures side by side have a maturity about them. They appear much more realistic - the faces are expressive. Yet the two figures have a "strung-up" look about them as though they are hanging suspended in mid-air. The shoes/feet do not seem to support the bodies - there is no strength in them. This young man is permanently in a wheelchair and would have difficulty moving unaided. The arms of both the male and female lack strength and action. I think the pictures are fairly accurate representations of what's real for him.

(E) Male aged 16 (Muscular Dystrophy)

This young man, small for his age and nicknamed "Midg" has drawn muscular type male and female pictures. The drawings are full of detail. The face is somewhat squashed and there is a hint of sadness about it. The hands are pointing down - again somewhat stiff - the feet are firmly placed on the ground - the arrows seem to point at rather shaky knee joints.

This young man has a tracheotomy and a limited life expectancy. In his drawing of the female - the same detail is found. Both male and female are in a sense fantasy figures far different from his own small frame. He was the only one to add words to a picture and note he gets the female to ask the question which, I believe, is the underlying question that he is asking himself.

The general discussion was introduced by asking them to talk about themselves and their disability. The comments which emerged are as follows.

2. *Discussion on Disability*

After an initial silence - these thoughts were expressed:

It makes life harder.

You can't play football or cricket.

In a wheelchair - you can at least get around but sometimes you just get stuck then you realise you have to wait for someone to help you.

Physical Appearance

Physical appearance is different. When you go shopping you get treated worse, like an invalid - people just stare at you - then you begin to feel sorry.

Want to be treated like normal.

There is a sadness - knowing you can't do things for yourself.

Jobs

Boys For me the best job would be in computers.

I can sit down and my wheelchair's no problem.

I'd like to be a football commentator.

Girls I'd like to be a secretary/receptionist - a job where you don't have to stand up too long.

I'd like to be a nurse - to help people.

When it comes to thinking about jobs it's hard to be realistic.

Makes life tough.

Relationships (boy/girl friend - marriage)

When the subject of relationships and sex was introduced - there was a lot of discomfort and much mirth.

The first comment was: "Don't like being alone". This was from someone whose life expectancy was limited.

We talk about it (sex) a lot ourselves - joke about it.

But we never really think about these things seriously.

Don't know why we joke about it.

Hiding the reality

Most of our lives we are taught not to talk about our disability or how it affects us.

No one ever talks about it.

It's really not worth talking about it.

People don't talk about it openly - we're told - it's private - disability is private - guess we want to deny it.

The group expressed feelings of frustration, embarrassment and anger about their disabilities but faced the fact that they had to accept them. One lad, revealing a high degree of maturity, stated that it was necessary to get a balance between frustration and acceptance.

I guess that is reality for them. They are disabled and it limits them considerably when compared with non-disabled people. But in the end, the meaning to their existence hangs in the balance, between frustration and acceptance.

Human figure drawings obtained from adolescents who are hospitalised for illness are reflective of the disturbed body-image which they are experiencing. It is important not to try and read into these drawings more than was intended by the person. However, it is clear that the pictures reveal hidden issues which it is probably helpful for the disabled adolescent to be able to ventilate and verbalise.

My suggestion would be to take each individual and explore with them the meaning of the drawing. I am sure that with sensitivity a lot of hitherto "forbidden feelings" about their disability would surface. This is in no way to suggest that these disabled adolescents are psychiatrically disturbed, but rather, with their disability, they are reacting normally. Frequently, for disabled people, the opportunity to talk about their disability and how it affects them is limited. If, by drawing human figures, an opportunity is provided to express what it means to be a disabled adolescent, then it seems to me it has merit.

It is an area which is well worth exploring in more detail and I would hope for the sake of disabled young people, this will be the subject of more formal and rigorous research.

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